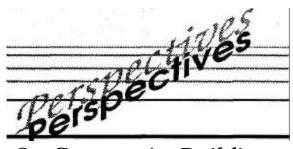


# More Than Just a New Address Images of Organization for Supported Living Agencies

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On Community Building

Reports in the Perspectives on Community Building series discuss issues of concern to those who are working to increase the presence and participation of people with developmental disabilities in the neighborhoods, workplaces, schools, and associations that constitute community life.

These papers are based on visits to innovative human service programs and focus group discussions. Program visits include intensive interviews with program leaders and staff, and usually with some of the people they serve. Discussions include people with different interests and points of view: people with developmental disabilities, family members, people who provide and manage services, people who make policy and manage service systems, and others who work for stronger, more inclusive communities.

Preparation of this report was supported through a subcontract from The Center on Human Policy, Syracuse University for the Research & Training Center on Community Living. The Research & Training Center on Community living is supported through a cooperative agreement (Number H133B80048) between the National Institute on Disability & Rehabilitation Research (NIDRR) and the University of Minnesota Institute on Community Integration. Members of the Center are encouraged to express their opinions; these do not necessarily represent the official position of NIDRR.

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#### Introduction

The director of an agency that has moved from operating several group homes to providing supported living described her experience of the change like this.

When we decided to change from group home to supported living, I thought it would be good for the people we serve. At first, I didn't think much about how our agency would have to change beyond figuring out how to find apartments and getting staff used to dealing with people in different locations. The change has been good, for all of us. But a lot more has had to change about the way we do things than I ever thought. Doing supported living is more than just getting people a new address.

From Residential Service to Supported Living

People with developmental disabilities can live well in their own homes if service system and agency managers can implement significant changes in the way people receive the assistance they need.\* A growing number of innovators identify this change as a shift from residential service to supported living. Supported living means providing people with disabilities the individualized help they need to live successfully in a home of their choice. It contrasts with residential service, which groups people with disabilities in residential facilities for the purpose of training or treating or caring for them. Residential facilities may be large, like institutions or nursing homes, or small, like what some people call "family scale group homes" or "apartment living programs." Making the shift to supported living involves more than providing a different location or a different type of service. The shift requires organizing and managing systems and agencies in new ways, ways that challenge common mental pictures of how organizations work and how they change.

The discussion and interviews at the base of this report asked people who are experienced in developing and managing supported living agencies to think about this question:

What is different about the way people organize their agency when the agency works to support people in their own homes and in community life instead of working to provide care and treatment in a residential program?

Some new images of organization and agency management emerge from considering their reflections on this question.

<sup>\*</sup> For good descriptions of several current approaches to supported living see S. Taylor, R. Bogdan, & J. Racino, eds. (1991). Life in the community: Case studies of organizations supporting people with disabilities. Vol. 1. Baltimore: Paul Brookes, Particularly relevant are chapters 7-11, chapter 14, and the editors' summary of the characteristics of responsive organizations in Chapter 18.

#### This report has three parts:

- PART I identifies some of the struggles in shaping an organizational culture that offers people with developmental disabilities good support to experience a dignified life in community.
- PART II focuses on issues of structure and power in supported living agencies.
- PART III describes the effects of competing ways to understand what organizations are and how they change on the effectiveness of supportive living agencies.

#### In preparing this report we drew on

- A series of working group meetings and interviews with members of the Washing ton State Residential Service Guidelines Task Force that took place in March and May of 1991
- Interviews with staff and managers from Training Toward Self Reliance in Sacra mento, CA in December 1989 and April 1991
- Interviews with board members and managers of Residential, Inc., New Lexington, OH in 1988, 1989, 1990, and 1991
- Interviews with staff and managers of Renaissance House, Tiffin, OH in February 1991
- Discussions with managers and staff of Options in Community Living, Madison, WI in 1988, 1989, 1990, and 1991
- A June 1991 working group meeting in South Onondaga, NY with Kathy Bartholomew-Lorimer, Gail Jacob, Beth Mount, and Steve Taylor.

We are grateful for all of these people's hospitality, openness, and thoughtfulness in identifying and discussing difficult and complex issues and we hope we have not distorted or oversimplified their concerns and insights. We also appreciate the comments of our colleagues Jack Pealer, Julie Racino, Mary Romer, and Steve Taylor on a draft of this report. Of course, we remain responsible for its content.

### I. New values call for a new organizational culture



Since 1983, the Washington State Division of Developmental Disabilities has supported a statewide learning process designed to build consensus on the desired outcomes of the state's residential services. Important activities in this process include:

Maintaining the Residential Guidelines Task Force, a committee which includes managers and direct service staff from residential service providers; representa tives of People First, a statewide self-advocacy organization many of whose members reside in services; the state ARC, an organization representing the interests of many families with disabled members; the state Developmental Disabilities Planning Council; regional case management staff; and county and state officials with responsibility for the development, coordination and operation of services. The task force acts as a focus for learning about residential services and has debated, drafted, disseminated and revised several statements about service direction and regulation based on comments and criticisms from many people.

The Division of Developmental Disabilities wants people who receive Residential Services to experience these benefits:

- Health and Safety
- · Power and Choice
- Personal Value and Positive Recognition By Self and Others
- A Range of Experiences Which Help People Participate in the Physical and Social Life of Their Communities
- Good Relationships with Friends and Relatives
- Competence to Manage Daily Activities and Pursue Personal Goals

These benefits characterize good quality life for all people and people with developmental disabilities should not be deprived of them because they need special services to meet their special needs.

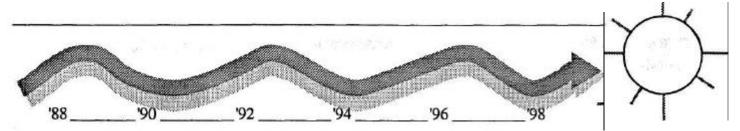
Effective residential service providers learn to offer necessary assistance with housing and daily living in ways that increase people's experience of these benefits. Since each person has unique preferences for realizing these benefits and makes unique decisions when facing conflicts among them, this learning process will challenge every program's capacity to offer individualized services. Because current regulations governing residential services focus on different requirements, implementing these requirements may require planned change in the organization of a program's resources.

• Convening an annual, statewide conference in Ellensburg WA which brings together a large number of service workers, service managers, and people and families who use services to share their experiences and to hear from innovators in community services and leaders in community building from outside the disability field from across North America. This conference provides an annual forum for discussion of progress and problems in understanding and implementing the directions under consideration by the Residential Guidelines Task Force.

- Offering technical assistance to residential service providers which allows them to hire people to assist their agencies. These activities focus on improving agency capacity to train staff and make organizational changes necessary to create the benefits identified as desirable by the Residential Guidelines Task Force. Some technical assistance is offered in workshops and some is in the form of agency consultation.
- Supporting five residential service providers to implement pilot projects under the guidance of the Residential Guidelines Task Force. Pilot agencies engaged in planned organizational change projects in order to test different approaches to creating and measuring the benefits described in the guidelines. Each pilot agency received a small amount of money to free staff time for change activities and to allow agencies to hire consultants of their choice to assist their work. Members of the Residential Guidelines Task Force monitored each pilot project, sponsored an external evaluation of changes resulting from the project, and held retreats to encourage exchange among pilot project participants. Representatives from each project joined the task force.

Greater clarity about the benefits supported living should offer people creates tension with current agency structures and procedures and the way staff jobs are organized. Out of this tension, new ways to organize can grow.

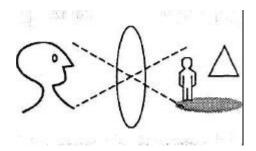
The pages with the lines at the top and bottom [5-13] summarize some of what members of the Residential Guidelines Task Force have learned about organizing to support people in community life by depicting the images of change they shared in two retreats.



Insuring that agencies support people with developmental disabilities to have valued experiences calls for long term personal and organizational learning. The challenge is to continuously clarify what the benefits mean through a process of developing practical ways to support a growing number of people to experience these benefits.

#### **Benefits**

- Health & safety
- Personal power & choice ,
- Status: Personal value & recognition
- Integration: Participation in , community life
- Relationships with friends & relatives
- Competence to manage daily life & pursue personal goals



Agency focus on these benefits doesn't define a model or a set of answers. Awareness of the benefits works like a lens. By discussing the meaning of the benefits, developing ways to approximate measurements of the benefits, and continuously improving the effectiveness of their work, people who provide support learn to see in new ways. They learn to see the person who relies on them for assistance as an individual who belongs in the context of community life. This new way of seeing leads to better understanding of each person, more knowledge of local communities, and a growing understanding of what it takes to support people to take and keep their rightful place. Each time people act on what they see, they refine the lens.

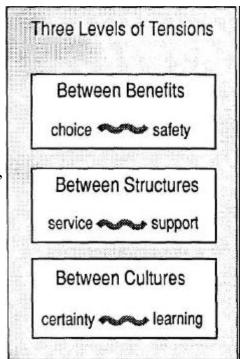
Acting to support valued experiences challenges all of the levels and relationships among participants in the existing system of services. People at each level have to strengthen their ability to participate responsibly in equal relationships and decrease their dependence on top-down controls. Relationships have to become strong enough to allow people to figure out complex issues together.

#### **System Levels**

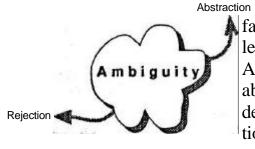
- I. Person to person.
- II. Staff member to agency
- III. Agency to agency
- IV. Agency to funders & regulators

People who take the benefits seriously experience three different levels of tensions:

- Each benefit makes an important contribution to the quality of a person's life, but discovering the way to experience each benefit and achieving harmony among them is the project of a lifetime. People make choices that put their safety at risk; close relationships often constrain choices; moving out to participate and exercise new skills can threaten relationships. The more limited people's experiences have been and the less able people are to speak for themselves, the more complex these tensions will be.
- Most stakeholders (from funders to family members) expect the residential system to offer highly specified packages of service to people grouped by disability label, often in special buildings, and almost always in isolation from community life. Boundaries between day, residential, and case management systems are supposed to be clear and distinct. Offering individual support on the basis of people's choices, abilities, and place in the community turns these expectations inside out.
- The culture of most provider agencies expects and reinforces certainty: job descriptions and policies define clear staff roles and responsibilities; professional teams and human rights committees make individual plans that authoritatively guide everyone's behavior in difficult situations; objective inspection guarantees accountability. Learning how to identify and do what it takes to assist individuals calls for willingness to live constructively with ambiguity.



To avoid the discomfort of ambiguity, people retreat into

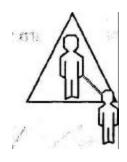


false certainty or leap into abstraction. False certainty leads some people to reject the benefits as "unrealistic." Abstraction lets people avoid what they need to find out about particular situations and specific individuals by debating about hypothetical examples and general questions. Because people live in ambiguous situations, the best way to deal with ambiguity is to stay with it and work to figure out particular situations involving real people.

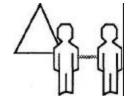
Concern for benefits structures Blocked energy & frustration

Service providers who have worked to understand the benefits through action have often discovered that their existing structures and arrangements are shaped wrong: they eclipse the energy that flows from a clear focus on the benefits. Some providers have had to face obvious incompatibilities between group living arrangements and individual benefits; others, in apartment living programs, have had to redefine their jobs from a focus on training people in apartments to supporting people in community settings, roles, and relationships.

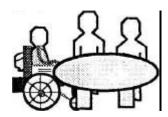
Most existing services are based on unequal, hierarchal relationships. Direct service workers, who are themselves at the bottom of the organization in status, salary, and influence over organizational resources spend most time with the people who rely on the agency. They are accountable to those above them to carry out instructions. Often, their relationship with the person they support mirrors their relationship to their agency: they act as if they were in charge of the person they assist and expect the person they assist to be accountable for following the instructions they pass on. Agencies that support valued experiences strive to form and encourage equal relationships between the people who offer assistance and the people who rely on them. A person with a disability has the best chance to experience benefits in an equal relationship with someone who is able to listen and who has influence over the way the support agency uses its resources. Of course, this means that agency administrators have to be willing and able to negotiate with funders and regulators for their own ability to influence the way their agency resources are used.



From...

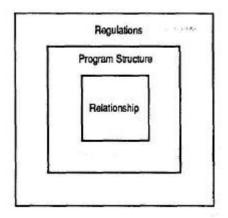


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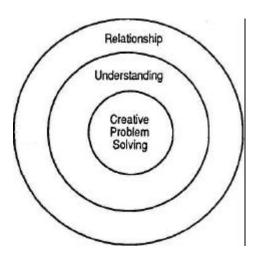


Many large and small changes in organizational systems and structures will be necessary to align available resources with the kind of staff activities that offer people real benefits. An agency supporting valued experiences needs a management team committed to improving their administrative, organizational, and supervisory skills as they deepen understanding of the benefits.

The context for thinking in typical agencies...



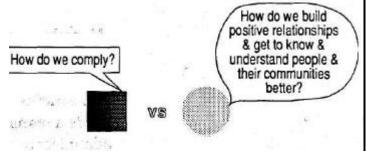
...shifts as agencies learn to support valued experiences.

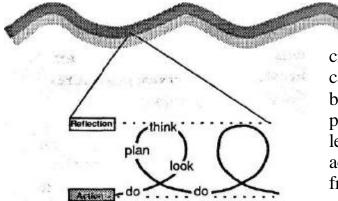


Implementing services that support valued experiences calls for a new way of defining opportunities, understanding issues, and solving problems. In short, it calls for a new way of thinking together. This new way of thinking begins with a shift of context.

- ? In typical programs, action supposedly flows from state policy and regulations to local program structure. Regulation and program structure form the context for the relationship between the person as sisted and the people who provide assistance. Admin istrators encourage staff to check their actions for conformity to individual plans, agency policies and procedures, and state regulations. Staff ask supervisors and technical assistants for cookbook approaches to problem solving which will protect them from liabil ity for mistakes.
- To learn to implement the guidelines, administrators and staff shift the context of their work. They aim to make action flow from relationships with the people they assist. They work to merit people's trust by lis tening carefully and responding truthfully and consis tently to what they hear. Better understanding of the person's interests and needs grows from relationships and focuses problem solving. Administrators encour age staff to think and act creatively to develop oppor tunities and overcome obstacles. Creative problem solving includes figuring out ways to deal with regula tions and take account of liability concerns. Staff ask administrators and technical assistants to join them in improving their problem solving.

To see the contrast between these two contexts, think about the practical difference between these two questions. Staff who answer the compliance question will see, act and learn differently from staff who answer the relationship question.





learning process move people and agencies along the long wave of change toward greater capacity to offer people benefits. Working inside the boundaries defined by the guidelines, staff join the people they assist and other community members to learn by moving from action to reflection and back to action. This process means regularly taking time out from action to stop, to look at what's working and what's not, to think about what lessons the current situation offers, and to plan for the next steps. Effective administrators encourage this process both around individuals and for the program as a whole.

Many, many repetitions of this simple

Most often reflection will be informal, a part of everyday work. More structured forms, like personal futures planning or retreats, offer opportunities to reflect on bigger chunks of experience.

Offering services that support valued experiences means building an organizational culture that will sustain effective relationships and continuous learning. People who provide direct assistance build up an effective culture when they act more creatively in their everyday work. People in administrative roles build up an effective culture when they model the necessary qualities in their own lives and in interaction with the people and programs they supervise. The more funders and regulators understand and encourage the kinds of behavior that allows effective problem solving, the less they will inhibit the development of effective organizational cultures in the agencies they depend on to serve people.

Administrators concerned with keeping learning alive will keep raising questions: "Are our values alive?" "Is our work satisfying?" "Have we mindlessly fallen into routine?" Effective administrators at every level of the system will make time to gather people together to deepen their understanding of the values and organizational qualities necessary to offer people real benefits. Budgets, job descriptions, supervision and staff development processes will reflect growing understanding of the qualities that distinguish an effective organizational culture.

# In an organizational culture that supports valued experiences

Commitment to vision is

OK. Ambiguity is OK.

Questions are OK.

Trying new ways to look at and do things is OK.

Looking at yourself and your own life is OK.

Asking for help is OK.

Personal involvement with people you assist is OK.

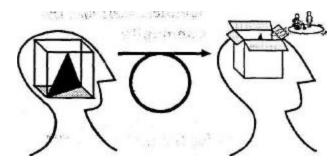
Working outside usual program boundaries & routines is OK.

Reaching out to involve new people in our work is OK.

Negotiating for what you believe people really want & need is OK.

Taking time to reflect & to invest in learning new things is OK.

### A new way to work calls for a new mindset



An important aspect of change is developing a new mindset: a different way to think about and evaluate situations. A mindset that focuses staff attention only on carrying out service procedures locks staff and the people they support into a narrow range of options. People experienced in implementing the guidelines call this "being in the box." What's needed is a mindset that "opens the box" and focuses attention on people in the context of their communities.

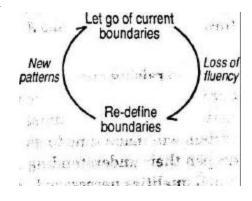
Staff who increase the benefits that people with disabilities experience don't just act differently from staff who deny or miss opportunities for greater benefits. They notice different things and think differently about them. Their work requires them to be able to...

- Think on the spot
- Negotiate shared understanding of situations among people who often have conflicting views
- Try things and test whether or not they improve the benefits people experience

Changing your mindset isn't as easy as changing your shirt. It involves letting go of the current boundaries that describe jobs and define priorities and re-defining boundaries that include more attention to differences in individual interests and circumstances, more attention to community opportunities, and more attention to negotiating better relationships.

Experienced staff say that this change is like learning a new language. There is a movement away from the familiar that feels uncomfortable because it involves loss of fluency and self-consciousness about choice of words and frequent errors.

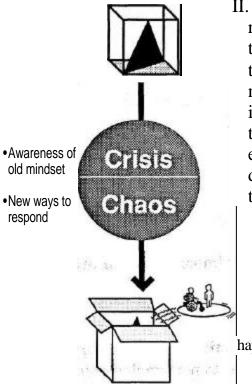
As new patterns emerge, so do new opportunities for deepening understanding of people and their communities.



Three kinds of actions help people make the shift to a more open, benefit focused mindset.

I. Bring together people who care about a person and other people with responsibilities to that person and strengthen their relationship with the person and the bonds between them. The purpose: to clarify and increase commitment to the person and to find common direction in varied ideas about the person.

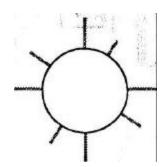




- II. Increase awareness of the ways current boundaries and rules get in the way of taking responsible action and work to re-negotiate these constraints. Crisis situations —situations that hold the threat of chaos- offer excellent opportunities to strengthen a new mindset. Acting constructively in crisis means moving into chaotic situations rather than trying to escape them. The challenge is to be part of an emotionally charged situation **and** think about how to redefine the situation so that the people in it can act in ways that will increase benefits. The process is simple:
  - Notice that we are acting and thinking as if we were "in the box."
  - Identify some of the specific ways we are acting and thinking that either makes the crisis worse or frustrates the accomplishment of some benefits for the people involved
  - Try out new ways to think about the situation and new ways to act.
  - Invite people from outside our local chaos to help us see what is happening and what options we have

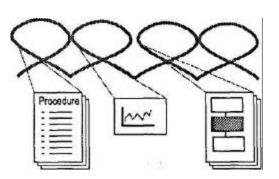
#### III. Learn to discover and communicate visions that...

- Clarify answers to the basic question that defines the relationship between a person and those who provide service: "Who is this person and who are we in this person's life?"
- Make it obvious that the person and those who care about the person and the people who provide service are in partnership to improve life together. "What do we want to be doing together in a better future?"
- Energize the hard work of changing our mindset by working to over come barriers to change and acting responsibly in crisis situations.

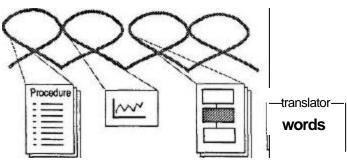


Leaders of agencies that have worked to support valued experiences say that they have had to invest time in building a shared understanding of the benefits. People need an organized process to clarify their understanding of the benefits, debate their importance, and define ways to act that will increase the benefits people experience. This process of change can be organized around designing and testing ways to measure changes in the level of benefits people experience and by modifying policies and defining new procedures. But the written results of undertaking these tasks are a better record of where the agency has been than they are a recipe for producing a better future. As one person said, "The investment in setting up new measures was well spent. It helped us make some important transitions. But now we don't make as much use of them as we did. We still take the measures, but now they are less important because we have learned new ways to talk and work with the people we support."

# A learning process generates written products...



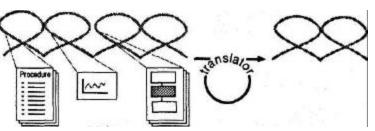
### ...but written products don't create organizational learning

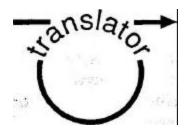


This discovery has important implications for the process of helping more agencies to implement the guidelines. Bureaucratic thinking would lead to the conclusion that the necessary changes can be effectively translated from innovating agencies to new implementors in words. From this point of view, a new agency simply adopts policies, procedures, and measurement and planning systems from an effective pilot. Training and technical assistance focus on transmitting the products from pilot sites.

Experienced implementors of efforts to support valued experiences fear that reliance on words alone as the translator will create what has become their nightmare: the words will change but people's experiences won't. Even worse, more subtle measurements could lead to even greater control of people's daily lives.

Dissemination of what the pilot projects have learned calls for the development of better translators of the pilot project's experience. Better translators get new implementors involved in their own pattern of learning through reflection on action. New implementors can't be consumers of products developed by the pilots or passive recipients of teaching and technical assistance; they have to become producers of change in their own communities. New implementors can't hold the people who assist them responsible for telling them sure-fire solutions to the problems that come along with implementing support for valued experiences; they have to take responsibility for learning for themselves with the guidance and support of people who are more experienced.





Agencies that want to begin to support valued experiences can accelerate their learning by...

- Listening carefully to descriptions of the processes other agencies have followed and thoughtfully designing their own change process based on what they have learned.
- Studying the products of other agencies' change efforts and using them as stepping stones in the development of their own policies, procedures, and ways to gather information about people's experiences.
- Getting involved in active learning experiences that give people a chance to try out some of the actions that can shape a new mindset. Some pilot agencies have found the Framework for Accomplishment\* workshop helpful for this kind of try-out.

<sup>•</sup>Framework for Accomplishment is a process for identifying the capacities a service program needs to develop in order to assist people to move toward a desirable personal future. One support to change in Washington state has been a series of intensive workshops which give people experience with using the Framework for Accomplishment process.

### II. Supported living calls for new structures & new uses of power

Effective supported living agencies are well structured and powerfully led, but they look and feel different from typical human service agen-

ties. The structures and the forms of power that shape and guide them differ from the bureaucratic patterns of organization and management common in residential service agencies because the nature of a supported living agency's work differs fundamentally from the work of a residential service agency.

Reasonable people might wonder whether it makes sense to think about supported living agencies at all. A small and slowly growing number of people with severe disabilities do not rely on agencies to provide the support they need, nor do they depend completely on the help of family members. They, or their families and friends, raise and manage necessary funds and organize a support system for themselves. They resolve the question of structure without agency intervention.\*\*

The notion of replacing agency-client relationships with consumer control in a personal assistance marketplace has many appealing features, especially to people worn out by the inflexible, costly clumsiness of bureaucratic systems. However, most people with developmental disabilities who live outside their parent's home or a residential facility now depend on a supported living agency because current public policy severely restricts people's option to control their share of available funds. And even when people with disabilities gain full control of available cash — as we believe they should— it is reasonable to assume that some people will probably choose the convenience of purchasing services from a supported living agency over the investment of time required to self-manage a personal support system.

Whether a supported living agency is legally organized as a non-profit corporation or as a cooperative owned by those who use its services; whether board and staff members have disabilities or not, the way the agency resolves problems of structure and power determines the quality of life for those who rely on it for support.

<sup>\*</sup> This section is based on a working group discussion with Gail Jacob, Kathy Bartholemew Lorimer, Beth Mount, and Steven Taylor which focused many of the findings from our field visits to supported living agencies. We also acknowledge Jeff Taylor and Aaron Lemle and Fiona Farrel for their contributions to our working group.

<sup>\*\*</sup>For a description of a complex, personally managed support system see J. Pierpoint (1990). From behind the piano. Toronto: Inclusion Press. The World Institute on Disability outlines the necessary policy foundation for a user controlled personal assistance system in S. Litvak, H. Zukas, & J. Heumann (1987). Attending to America: Personal assistance for independent living. Berkeley, CA: World Institute on Disability. John McKnight (1989). Do no harm: A policymakers guide to evaluating human services and their alternatives. Evanston, IL: Center for Urban Affairs and Policy Research, makes the case for preferring income re-distribution to service provision as a primary role of government.

#### Structure\*

come-in/ live-in assistant(s)

#### **Assistive relationships**

The fundamental structure at the foundation of a supported living agency is a set of relationships between a number of people with developmental disabilities and their assistants. Each person will have a unique and changing mix of personal assistance based on the person's preference and need as the person's preferences and needs emerge in the relationship.

- Some assistance involves instrumental matters such as getting dressed, eating, communicating, going to the toilet, keeping house, shopping, getting to appointments and activities, and managing money. This help may be from a person who lives-in with the per son with a disability or, more commonly, from a person who comesin to help on schedule and as needed. Many people will receive assistance from more than one person and some people will have additional helping relationships with tutors, or counsellors, or communication or physical or occupational therapists. Sometimes, instrumental assistance will involve helping the person to develop or improve their skills; often, the assistant will perform tasks that the person cannot efficiently do alone.
- Some assistance involves helping a person to plan and coordinate their activities and their come-in and live-in help. This help may involve determining the person's preferences and needs about type and location of housing; selection of roommates if the person wants them; transportation arrangements; finding and scheduling activi ties that offer the person opportunities to pursue personally inter esting goals; hiring, training, scheduling, supervising, and firing assistants; and personal problem solving. For many people with developmental disabilities, this role will be like that of an executive assistant: taking responsibility for carrying out the tasks the per son with a disability delegates in the way the person prefers. For a few people with substantial cognitive disabilities the assistant will be much more active in interpreting the person's preferences based on their involvement with and observation of the person. For some people the assistant's role will be complex because the person will be able to assert clear preferences in some situations and will find other situations extremely challenging.

The diagram above shows a three person relationship, separating instrumental assistance from assistance with planning and coordination and assigning some supervisory responsibility to the planning

\*It is hard to write



descriptively about structure without sounding as if we are prescribing the one best way. Remember that we abstracted these descriptions from several different but effectively organized supportive living agencies. Each agency has its own distinct and evolving ways of structuring itself. assistant. In practice, it is very common for the person who provides planning assistance to also offer help with everyday tasks, and many people will have only one helper who combines both functions. Some people will have more than one live-in or come-in assistant. Whatever the configuration, its emergence from the particular situation of the person with a disability involved is the hallmark of supported living.

Being a good assistant challenges each support worker's capacity to sustain a close working relationship. In the context of this relationship, depending on individual circumstances, support workers may be called onto...

- ... identify and help the person to respond to potential opportunities and potential dangers in their situation
- ...facilitate people's problem solving efforts
- ...help people interpret and make sense of matters as diverse as apartment security deposits, or the results of medical tests or the possible reasons for a neighbor's hostility
- ...advise people in matters of importance to them
- .. .represent people's interests when they have conflicts with landlords, bus drivers, police officers, service providers, physicians, income maintenance workers and others
- ...assist people in identifying their strengths and interests and the ways they can pursue them.

Maintaining any good working relationship is difficult. Assistive relationships can be particularly complex because...

- ...sometimes the support worker has multiple responsibilities: 1) to follow the instructions and respect the preferences of the person with a disability; 2) to help the person discover what their preferences are; 3) to interpret a person's preferences when severe cognitive disability makes the person's preferences uncertain; and 4) to protect a person who is vulnerable
- .. .the person with a disability depends on the support worker for vital assistance and so may try to please the support worker rather than asserting and negotiating their own needs and preferences because they feel vulnerable to the support worker's goodwill and threatened by the possibility of the support worker's disapproval
- ... the person with a disability may have poor supervision skills and poor negotiating skills so that the support worker feels mistreated and frustrated

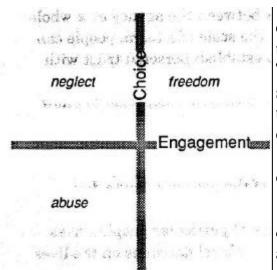
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.support workers share, often unthinkingly, in strong cultural prejudices that can easily lead them to treat people with disabilities as less valuable and less capable than themselves

.the disabled person's past experience of services may offer them little confidence to trust the support worker: the person with a disability may have been abused or ignored by support workers, or may have had repeated experience of losing good support workers to high turnover

.in many ways people with disabilities live in a hostile environment — many of the people they meet will devalue them, a few will openly reject them because of their disability, and a few will exploit their vulnerability; this means that the support worker has to assist a person to assess and deal with risks without either being naively optimistic or unrealistically pessimistic about other citizen's responses

.support workers have to stay clear about the ways in which their personal preferences and values may differ from those of the person they support and keep re-creating ways to avoid imposing on the person they assist without compromising their integrity.



Support workers' jobs are complex because they are closely involved with socially devalued people who need their daily help with important matters in their lives. This diagram illustrates just one of these complexities by suggesting that individual freedom is, among other things, a matter of both choice and personal involvement or engagement. No one is free without choice and no one

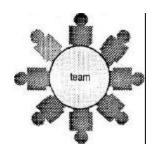
is free unless what they decide matters to some others.

Policy and practice have routinely denied people with *overprotection* disabilities choice, thus trapping them in abusive or overprotective situations. Supported living agencies properly commit their workers to actively

promote people's choices. But policy and practice have also routinely discouraged committed, personal engagement with people with disabilities. Often this has extended to isolating people by breaking people's relationships with their families and disrupting potential friendships among people with disabilities. Disengagement creates an abusive situation when people are also denied choice and it sets up a potentially neglectful situation when people can decide for themselves but no one is personally engaged with them. People who are isolated face a much increased risk of being exploited. Support staff who stand back and let isolated people sink into difficult or

dangerous situations without comment or effort because "our agency gives people their right to choose" or "we believe in friendship and choice and she picked an abusive friend" are simply neglectful. Support staff who work to strengthen their relationship by identifying and attempting to negotiating their differences with a person's choice may contribute to increasing the person's freedom, but the costs of such increased engagement often includes confusion, emotional conflict with the person, self-questioning, and failing to influence the person's choice.

#### The team\*



Membership in an effective team helps support workers to be better participants in their assistive relationships. The team offers the support worker a place to figure out what is happening in complex situations. It provides colleagues who can offer empathy, suggestions, and resources while they pose questions and challenge apparently narrow or prejudiced perceptions or actions. An effective team serves as a focus for personal and organizational learning as team members reflect on their work and plan ways to improve their effectiveness.

The team provides a human-scale link between the agency as a whole and the people the agency supports. At the scale of a team, people can get to know one another well enough to establish personal trust with one another and to identify ways that they can help one another both one to one and as a group. Team members can, in time, come to know the people with disabilities the other members of the team support and thus provide informed back-up from a known person when the support worker a person usually relies on is unavailable. Teams can self manage the details of scheduling and much of the agency's day to day problem solving. Team members can identify necessary agency or system changes based on their knowledge of particular people's lives and carefully evaluate the impact of agency level decisions on the lives of the people who rely on them.

An effective team leader collaborates with team members to develop, renew, and deepen commitment to the values and direction the supported living agency stands for. Through individual coaching and group leadership, the team leader collaborates with members to improve each member's ability to realize their commitments in everyday relationships with the people they support. The team leader serves as an active link between the decisions affecting the whole supported living agency and the work of the team. This involves representing the

<sup>\*</sup>The team we discuss here is **not** the multi-disciplinary professional team whose control of disabled people's lives is licensed by many current regulations. It comprises and supports employees of an agency in their daily work.

team to the whole agency and the agency to the team. The all too understandable human desire to use groups as a place to flee from difficult issues into blaming or wishful thinking or unproductive fights makes effective team leadership a demanding role.

Some people raise an important question, "If staff need the support of a team, what independent opportunities do people with disabilities have to figure out what is going on and how things should be better?" When people with developmental disabilities have friends and involved family members, they have the chance to develop an independent perspective on the assistance they receive. When previous services have isolated people and discouraged them from reaching out to others, they have fewer options. Some people have found independent support among other people with disabilities in an advocacy group. A few people have formed relationships through citizen advocacy programs. A few people have formed circles of support, usually with outside help. A community that lacks such independent, organized responses leaves those people who need help to overcome isolation in a dilemma: they rely on support workers to assist them to form relationships independent of the support agency. Collaboration between people with disabilities and their support workers to overcome isolation is one of the most exciting and confusing areas of work in supported living.

#### The management team

The management team orchestrates the whole agency's learning about what its chosen values and direction mean and how best to realize them. The management team structures opportunities for people to invest their talents in developing the agency while they influence one another's appreciation of the agency's commitments. Some of their opportunities come in the form of training, but most arise from the work of managing the agency. Working groups take responsibility for such important tasks as evaluating agency performance, developing long range strategies and plans for management and staff approval, designing necessary processes, policies, and procedures, and developing the agency's position with outside resources such as funders, regulators, housing associations, or community development groups. To bring together different talents and points of view, working groups purposefully include people with developmental disabilities, support workers, management team members, agency board members, and other advisers.

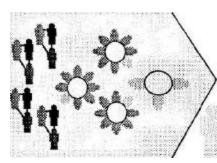


The management team assists the work of teams in two ways. First, it coordinates the daily work of the agency in areas where teams may interfere with one another's work due to common dependence on the same resources, such as secretarial services or housing resources. Second, it provides team leaders with the opportunity to develop one another's abilities by offering support in understanding their team's work and challenging and expanding one another's ideas and skills.

The agency director leads the management team and serves as the management team's primary link to the agency board.

#### The director

Most of the operational management of a supported living agency must happen where people have the information necessary to make operational decisions. The staff who provide planning and coordinating assistance need the judgement, problem solving, and negotiation skills to deal with most plans and problems in collaboration with the person they assist. Of course, placing responsibility for most decisions with direct service staff and the people they support doesn't require them to act alone. Indeed one of their basic skills is knowing when and where to go for help. Teams need the level of trust in one another, the level of commitment to the agency's direction and values, and the group problem solving skills to serve as the main source of learning, support, and coordination for support workers. A variety of workgroups, organized by the management team and the board, need the information and the skill to plan, evaluate, and design policies and procedures.



The director stays aware of the agency as a whole and exercises responsibility for maintaining focus on the agency's values and direction. Awareness of the agency as a whole calls for the director's personal involvement with assistive relationships and team learning. This represents one of the effective limits on the size of a supported living agency. A supported living agency risks being undermanaged when the number of people it assists plus the number of staff becomes too large for the director to

maintain personal contact. Responsibility for maintaining direction requires the director to carefully attend to the selection and development of team leaders and support staff and to the composition and preparation of working groups. The director needs more than the authority of position. The director needs the authority that comes from personal knowledge of people's situations and personal commitment to contributing to good solutions when difficult problems threaten to compromise the agency's direction and values.

#### Important environments

associations

places

regulators

service

system

provide

gant Units

Two different environments provide the resources a supported living agency needs to do its work. Because neither service system nor community are accustomed to supporting people with severe disabilities in their own homes, an agency can't passively adapt to what its envi-

> ronments expect of it. That would push all but the most determined and capable people with disabilities into residential facilities. An effective agency works community strategically to shape the service system and the community that contain it.

> > The service system. In most current instances, the

individuals service system provides the money to pay support workers and their managers and coordinates the supported living agency's work with other service providers (such as supported employment or day service providers). The service system typically coordinates both at the personal level, through some form of case management, and at the interagency level, through plans and contracts. The service environment can produce different kinds of conflicts; for example:

- Restrictions on the expenditure of available funds often limits the sup ported living agency's flexibility in matching individual needs and prefer ences with available resources. These restrictions increase the transac tion cost of providing services in at least two ways. 1) They impose forms of meetings and paperwork which are unnecessary to support particular individuals and which effectively move decision making power away from the person and those who assist for no reason other than to satisfy funding requirements. 2) Gaining waivers, permissions, and developing work-arounds in order to do what seems necessary absorb substantial time. Widespread system dependence on medicaid funds, which were intended to pay for sickness care, compounds this problem.
- Most service systems simultaneously operate different types of services with incompatible assumptions about people with disabilities. Many people who live in and control their own homes with support spend their days in mindless, segregated activities designed to treat and cure or "habilitate" their disabilities. This creates conflicting and confusing experiences for the person. Although the staff of differing agencies work within the same service system, they think about and do their work in different worlds. These fundamental differences in perception and relationship make conflicts across agencies hard to negotiate and greatly reduce the effectiveness of inter-agency coordination.

• Most current systems are built on the hierarchal assumption that people who provide direct service should be less competent and lower paid than the professionals who write plans. For examples, most systems assume that, because of their position, case managers have greater knowledge and far superior judgement about what makes sense for a person they meet formally and occasionally than the support workers who spend substantial time with a person every day. This leads service systems to the low expectations of direct service staff that result in underpaying and undersupervising the people in the best position to learn about and act for the person. It also creates incentives for agency growth because larger agencies can pay more people as managers or specialists.

Failures to make these conflicts into opportunities for small steps toward reshaping the service system impose their consequences on people with disabilities. Failure to succeed in particular attempts to change the service system can deepen support staffs understanding of the situation of people with disabilities and commitment to ally with them in making systemic changes that will improve everyone's life.

The community. Communities provide people with disabilities with places to live and work and learn, goods and services to buy, activities and associations to join, and people to make into friends.

Though some community members purposely exploit or act openly hostile to people with developmental disabilities, most discrimination and exclusion arises thoughtlessly from ignorance. Developers see no way and no reason to insure that they build accessible housing. Housing advocates create cooperatives and other new forms of housing on the mistaken assumption that people with developmental disabilities live happily in residential facilities. Landlords and neighbors and shopkeepers and dentists and pastors and police officers worry about unusual demands on their abilities and tolerance or unusual threats to their property, prosperity, and safety. Leaders of associations and activities more often see people with disabilities as a potential project than as a source of interested participants and members.

Supported living agencies most powerfully influence community environments when they assist individual people with developmental disabilities to establish themselves in homes of their own and support them to develop community connections that allow them to discover and pursue their personal interests. Agencies can also support and challenge the people and organizations responsible for housing and

improving the quality of neighborhood life to include people with developmental disabilities in their efforts, their memberships, and their agendas.

The supported living agency links bureaucratically to the service system. Most of the visible work of effectively positioning the agency in the service system gets done in formal meetings and written plans, budgets, reports, and justifications. To deal with the service system, the supported living agency has to be able to look and act like a formal organization -the triangles in the diagram. The director or the director's official delegates deals with agency matters. Staff with professional titles represent the agency in multi-agency individual planning sessions. Budget revisions and reports are filed on the correct forms on time. Agencies only violate these expectations with a purpose, otherwise the service system will be unable to hear the agency's communication. The less visible work necessary to keep bureaucracy from extinguishing purpose depends on agency leaders' ability to sustain good personal relationships with people who manage other parts of the system. These relationships allow the director to build trust and credibility and to make person to person requests for involvement in work on system changes.

The supported living agency links to the community in multiple, informal ways. Most of the work of effectively positioning the agency in the community gets done on the basis of personal connections. Who a person knows and what a person is willing to do are more important than a person's title in many important areas of community action. Most contacts are casual and paperwork is infrequent. To deal with the community, the supported living agency has to act like a source of community action —the circles in the diagram. The agency as an agency very seldom takes an explicit position. Most actions are individual because they arise from individual interests. Support workers assist the people they support to satisfy property owner's concerns about signing a lease or to investigate the possibilities for membership in a community group of interest or to prepare a covered dish for a neighborhood party or to negotiate an appropriate restitution for an offense with the local courts. Agency staff and interested people with developmental disabilities join a local housing action group to align their energy with the efforts of other citizens.

Building the capacity to assume two different shapes to influence two different environments organizes a good deal of a supported living agency staffs learning. Different environments require shifts of mindset as well as calling for different clothing.

#### **Power**

#### Forms of power

Leaders of successful supported living agencies identify the use of power as one of the most important and difficult issues in their work. Several of them find this way of distinguishing between three different types of power helpful in their work:\*

- **Power-over** other people arises from the ability and willingness to make decisions for others and to enforce their compliance by authoritative control of rewards and punishments. Typical systems and agencies embody the assumption that people higher in a hierarchy will exercise power-over the people beneath them. Professionals and staff unquestioningly expect that people with disabilities will do what they are told by those authorized to plan for them and see those who do not comply as further and more deeply disabled. Powerover others is the most common and familiar form of power. People expect its use, feel uncomfortable at its absence, fear the uncertain consequences of denying it, and easily fall back upon it in times of stress. "Real politicians" and "real managers" and "real organizers" rise and fall on their ability to manipulate power-over. But powerover others poisons the relationships necessary to support people with disabilities to take their rightful place in community life. This appears true even in structures that attempt change by swapping the order in a hierarchy so that the people with disabilities assume power over their helpers.
- \*A concise description of . these different forms of power is in Starhawk (1987). Truth or dare: Encounters with power, authority, and mystery. San Francisco: Harper & Row. Also see Marilyn French (1985). Beyond Power. New York Summit, Chapter 7. The notion of power- with is similar to the approach to conflict management developed by the Harvard Law School's Negotiation Project and described in Roger Fisher and Scott Brown (1988). Getting together: Building a relationship that gets to yes. Boston: Houghton Mifflin.
- Power-with other people arises from people's ability and willingness to listen to and be influenced by another's perceptions and suggestions and to offer their perceptions and suggestions in turn. Power-with requires the kind of respect that grows with a willingness to be personally involved with one another and to share by choice in a common project that will shape and shift patterns of relationships among people. Differences provide information and the occasion to clarify and strengthen relationships by negotiating creatively. Because power-with depends upon and reinforces cooperation, its exercise depends on people's mutual restraint and willingness to learn from their experience together. Not all exchanges of influence have positive motives or good consequences, so people need to assume responsibility for questioning and testing the fruits of their collaboration. Power-with defines a strong foundation for the kinds of relationships necessary to support people with disabilities in community life. service in the part of worker of the the state of the s

• **Power-from-within** arises from a person's willingness and ability to discover and creatively express the abilities and concerns that they find spiritually meaningful. In civic life and in the world of work power-from-within brings people beyond seeking a role to finding a vocation, a calling. Power-from-within gives a person courage to act when important values are threatened, even if the short-term prospects for success are poor. Several leaders in supported living identify power-from-within as the source of their own ability to overcome their fears and doubts in order to create and protect innovations in difficult circumstances. Because power-from-within expresses a person's deepest beliefs, conflicts can be painful and very difficult to resolve; so many people learn not to share their convictions. People acting on the basis of power-from-within need to exercise personal discipline to sharpen their discernment of what ultimately matters to them and to strengthen their abilities to creatively express what matters to them in everyday life with other people.

Power-with and power-from-within have particular relevance for supported living agencies. Assistive relationships cannot be based on the coercion and fear that come with the exercise of power-over. Support develops on the basis of mutual influence through the support worker's listening and responding to the person with a developmental disability and, in turn, offering the person information, suggestions, guidance and identifying and negotiating differences. Even when there is a definite element of control in the relationship -as when a person has been declared incompetent to make money decisions or when a court makes some form of supervision a condition of release from jail—power-with provides the only constructive context for a support relationship. Either person's use of power-over marks trouble in an assistive relationship that can only be repaired by moving to the ground of power-with. Team relationships cannot be based on coercion and fear. Learning and mutual support require trust and the ability to identify and negotiate differences.

Community relationships cannot be based on coercion and fear. The supported living agency strengthens necessary community relationships by looking for common ground and supporting people with disabilities to make clear requests for inclusion, assistance, or adaptation. Even in the relatively few instances when these requests are backed by enforceable rights, outcomes depend more on creative negotiation and joint problem solving than on giving orders. As anyone who has lived with many attempts to do even simple things like make public build-

ings physically accessible will know, this is because there are so many nonfunctional ways that even well meaning people can give the appearance of compliance with rules. Assertion of rights gains most ground when it leads people to establish power-with relationships.

Although the context is hierarchal, relationships within the service system cannot be based completely on power-over because the supported living agency is low down in the hierarchy. Because of its position, the agency is expected to take and implement instructions from system managers and multi-disciplinary teams rather than to be a source of action. By establishing power-with relationships in the network of people who manage the service system, supported living leaders multiply their ability to respond to the individual preferences and needs of the people with disabilities their agency supports.

Power-from-within gives the people involved with supported living agencies the energy and courage to stand up to unjust situations, to continue to face and learn from difficult problems day after day, and to find meaning in their lives despite slow progress or failure. Many effective supportive living workers say that they are led and sustained by some people with disabilities they know whose power-from-within is very strong for those who take care to notice and listen to them.

#### Occasions of power

Assistive relationships form the daily testing ground for power-with and power-from-within. Each relationship includes many moments of truth in which people will either struggle for collaboration or fall back into coercion or withdrawal. Whether assistive relationships grow stronger from these tests depends partly on the people in the particular relationship and partly on the way the supported living agency develops as an organization.

Five recurring organizational issues test and strengthen the use of power in a supported living agency. They are: negotiating necessary resources; building effective teams; keeping balance between the work of the whole organization and the work of its teams; setting and maintaining direction; and, maintaining the agency's integrity.

Together, these issues provide the agency with chances to build up alternatives to power-over. Each issue offers the opportunity to shape stronger collaborative relationships and deepen understanding of the links between supported living work and what its participants find personally meaningful. The way an agency manages these issues determines the amount of energy it can focus on realizing its values. The

more practiced people become in organizing their efforts through the exercise of power-with and power-from-within the less organizational relationships will be dominated by power-over.

Any member of a supported living organization can constructively exercise power in each of these situations. Power-with grows when people intentionally draw and re-draw boundaries by moving toward some relationships and away from others. People strengthen the use of power-with in the agency when they...

- ...bring people together to focus on a common project, especially when this brings previously uninvolved people into the project
- ...encourage people to say clearly how they see and understand a situation and what they want from it
- ...inquire about the position of people who disagree or are unwilling to become involved in order to find out what it would take to gain the person's cooperation
- ...practice creative search for mutually beneficial actions
- ...advocate for suggestions that structure shared action
- ...cooperate with other's projects
- ...question limiting assumptions by inquiring why a desirable action appears impossible
- ... figure out ways to evaluate and learn from the effects of their actions

People strengthen the exercise of power-from-within in the agency when they...

- ...invest time in strengthening and clarifying their awareness of what is personally meaningful to them
- .. .look for ways that the agency's work offers chances to express what is most important to them, especially in frightening or confusing or discouraging situations
- ...speak clearly and strongly about their sense of what matters to them as valuable and fundamental, especially when their agency's behavior seems to be negative or out of control
- ...listen respectfully and thoughtfully when others speak of what matters most to them

#### Negotiating resources from the service system

Under current policies, supportive living agencies need to establish a good supply of six resources from some part or other of the human service system:

• Permission to serve people. Most service systems control eligibility, set service priorities, take the authority to decide or at least approve who an agency can serve, and control access to people with disabilities —especially those people with disabilities who are inmates of residential facilities

- Money to support people, and sometimes money to subsidize people's living expenses. Most service systems allocate funds for services and money for living expenses above disability benefits to agencies rather than to people.
- Legitimacy. Most service systems take the authority to license or approve service providers and most make such approval a condition of continuing operation.
- Flexibility. Inability to respond to changing individual needs and preferences makes supportive living impossible. Increasingly specific and detailed regulation and prescription of the details of agency relationships and behavior serves apparent rationality in public administration even as it destroys agency and system effectiveness. Supportive living agencies live or die on their ability to develop prob lem solving relationships with service system mangers who use instruments like waivers, new categories of program description and regulations, pilot projects, and innovation funds to create flexibility.
- Knowledgeable and credible advisors on how the system works.
- Information and influence on important issues. Service systems face uncertain pressures and the ways they choose to respond will matter a great deal to the capacity for supported living. Service system managers may choose to listen more closely and be guided more by supportive living providers than the size of their agencies or their apparent importance would suggest.

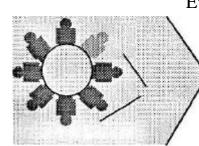
Two related strategic issues commonly arise in relationship to service systems. One poses the question of the scale and rate of growth of the agency. The other poses a trade off between flexibility and amount of available funds.

Service systems have a legitimate interest in offering good services to growing numbers of people. Successful supported living agencies provide an attractive service and are often uncommonly well managed

(even if the management style and the organization's structure seems odd). So service system managers are likely to press a successful supportive living agency to grow larger and to grow larger faster. Sometimes this comes as an explicit proposal, "We want you to double in size in the next three years." or "Another provider has lost their license; will you take over their agency and make it like yours?" Sometimes it comes implicitly in individual requests that accumulate to a similar outcome, "Won't you just find room for this one person who really needs you?" Supported living agency management has to maintain control of how large they become and how fast they grow. The difficulty of doing this can be compounded when board members or staff see requests for growth as a clear sign of success and uncritically conclude that the ability to offer good support to a small number is a clear sign of ability to offer the same quality to as many deserving people as the market will bear. Experience suggests caution: agencies that are well managed when small often become uncontrolled when scale or rate of growth turns personal leadership into distant management. Growth will inevitably demand substantial leadership ability and time and will almost certainly lead to at least a short term decline in the quality of support available. At least an agency that decides to grow needs to budget time and resources to learn how to grow bigger.

Money for services is scarce and many service systems predict that it will grow scarcer. This leads system managers to search for funds that have the advantage of availability and the disadvantage of bringing requirements that generate new levels of detail complexity for their system. Supportive living agencies that want to sustain good assistive relationships by being able to offer support workers decent wages and benefits may be offered a deal that allows them a higher rate of reimbursement in return for much more intrusive and inflexible regulations. Supportive living agencies that have carefully made a strategic decision to grow may well be offered the same deal. Flexibility is costly to achieve. Once achieved it is difficult to maintain and easy to lose. Trade-offs between increased money and decreased flexibility need sober evaluation and time for people to explore and align with whatever position an agency finally takes.

#### **Building effective teams**



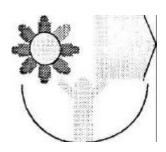
Everyone in the agency contributes to team effectiveness. The agency strongly influences team effectiveness through its personnel and staff development activities. Hiring team members and identifying team leaders are the most important operational decisions the agency makes. Creating ways to develop competence and leadership in team members and team leaders are the most important operational investments the agency makes.

Common assumptions that shape service systems can constrain effectiveness in hiring and developing people. Though the supportive living agencies we have studied have relatively low turn over, most systems assume that the people who offer direct service will do so for very short periods. This assumption makes investments in developing people look like a waste of time and money. So systems generate a vicious circle of underinvestment and adjustment to built in incompetence.

Every team faces two predictable stresses that have agency wide impact: Making decisions in situations where people's safety is threatened, and complying with requirements necessary to agency survival but irrelevant to people's sense of what matters in their work. It's important for the agency to systematically support teams in each of these areas.

Support workers occasionally have to make decisions where a person's safety or health or continued freedom to live in the community is at stake. The agency needs to support its workers in these situations by insuring that they identify these situations; that they recognize these situations as occasions to get help; and that they have a well organized process for thinking through the situation with others and in terms of the agency's values. The agency owes the people it supports and its support workers a framework for making these difficult decisions that is publicly and widely debated, endorsed by the agency board, and regularly reviewed and revised. This framework can't be in the form of simple instructions in the form, "If this... then do exactly this." So people need personal and team support to understand, apply, and learn from it. The issue of response to real threat to health or safety can never be finally resolved. The agency as a whole, like each assistive relationship where such threats arise, has to keep balance in a situation that can easily fall into neglect or overprotection.

As long as a supportive living agency has to function part time as a bureaucracy, support workers will have to meet requirements that have no clear relationship to what matters to them in their jobs. The agency can support teams to deal with this in at least four ways: 1) minimize the agency's reliance on intrusive funding sources and provide staff with opportunities to explore and debate the implications of the trade-offs the agency makes ["We'll be able to serve five more people and raise your pay. But these are the requirements you will have to take responsibility for meeting..."]; 2) continuously look for ways to decrease the cost of compliance, probably under the coordination of a working group composed of people who enjoy looking for ways to simplify and streamline routine work; 3) regularly review the actual costs of compliance with regulations and actively negotiate with the service system for release from damaging requirements; and, 4) recognize support staff who find ways to comply with requirements without compromising the quality of the assistance they provide.



Keeping balance between the whole organization and its teams Teams carry most of the day to day responsibility for supporting assistive relationships and an effective team will be a cohesive group. This has advantages for making good decisions and promoting learning. But team closeness can become a screen for moving away from the agency's values and direction or even a cover for poor performance of support work. Strong teams could mean a weak agency if there are not explicit investments in maintaining a balance between teams and the agency as a whole.

To manage this issue well the agency needs to adopt and apply the principle that any decision that can effectively be made by a person with a disability or those close to the person should be. No decision will be made at a point in the organization farther from the person with a disability than necessary. This means that any requirements for uniformity across teams need careful discussion and regular review.

Team leaders play an important role in maintaining balance. If they work actively to link the management team with the team they lead, they will help each group understand the whole organization better. Being an active link is more stressful than simply identifying with one group or the other. It's easier on the team leader to define the job as getting what their team needs from "the management" or telling "them" what "we" the management team have decided "they" are to do. The director's leadership in the management team has an impor-

tant effect on the way team leaders play this role. The director needs to insure that each management team member is responsible for keeping a view of the whole organization, which includes each team.

Working groups on agency issues give team members the opportunity to develop a perspective on the whole organization while they influence its direction and practice.

Team members help maintain the balance by proudly showing the organization signs of what makes them distinctive as a group. Inevitable feelings of competition between teams can be ritualized in agency customs, jokes, and folklore. Social occasions and agency ceremonies strengthen both people's sense of distinctiveness and their unity when these events include people with disabilities, support workers, and others involved with the whole agency.

Setting and maintaining direction

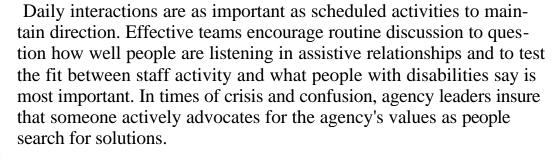
People involved in supported living need to be proud of what they do. And people involved in supported living need to recognize how easy it is

> to lose track of direction and compromise values in order to deal with the stress of daily relationships or to deal with environmental barriers. To develop personal and organizational competencies, the agency needs to schedule a balance

of activities to affirm and question its practice. Such activities include:

- Small and large celebrations of disabled people's struggles and victo ries
- Regular times for retreat and reflection
- Encouraging people to visit and form relationships with people who do similar work in other agencies
- Supporting participation in training and development activities outside the agency
- Regular agency evaluation, designed in collaboration with agency staff
- Encouraging people to balance their commitments to work with other important personal, family, and civic activities

Each activity offers a scheduled chance to affirm what is working well, check direction, question established practice, deepen understanding of values and the tensions the agency's commitments create, and define the agenda of issues important to the agency's next stage of development.







#### **Maintaining integrity**

Many people develop new skills and deepen their maturity through their struggles to provide people with disabilities with good support. No one does the job without confusion, problems, and errors, but people who are capable of doing the job learn from their experiences. When times are difficult for them, they may put other things before their responsibility to the people they support. It's important for colleagues, team leaders, and the agency director to be aware of these times in one another's lives so that they can confront the person involved, offer extra support, or make arrangements for the person to take a break.

Sometimes support work or team leadership simply doesn't suit a person's abilities and gifts. A person who recognizes the mismatch and moves on to other work does relatively little harm. People who keep working despite this mismatch threaten the supported living agency's integrity by putting their own needs and convenience before the needs and preferences of the people they support. The staff person in this predicament will find it as difficult to listen to the people they support and act on their behalf as to honestly share in identifying difficulties and problem solving with team members.

Sometimes a person who offers good support to a particular person lacks the personal integrity to be a constructive part of an agency. Such a person exploits team colleagues and undermines the trust necessary to effective working relationships.

The person whose own needs and interests don't match the demands of supported living work should find other work. Usually such a person will accept counsel, but occasionally it may be necessary for the supported living agency to act formally to terminate someone's employment. Because the agency needs to function on trust, it often take additional time to satisfy an employee's right to written evaluations which document performance problems, formal warnings, hear-

ings, and so forth. Sometimes these more formal procedures do allow a person to accept responsibility for their work, but often they do not.

Sometimes teams develop an agenda at cross-purposes with agency values. Usually this is less a conscious plan than a kind of an unconscious conspiracy. Instead of openly advocating for agency change, a team in this situation hoards its concerns and conflicts as a source of its own cohesion and sense of superiority. Effectively confronting the negative energy of such a group will call on all of the power-within the other people in the agency, especially the director.

#### The director's responsibility

The director has a particular responsibility to insure that the agency, through its assistive relationships, teams, and working groups, focuses enough power on these five recurring issues to insure that the organization keeps developing its capacity to realize its values. In a sense, the director acts as a trustee of the agency's direction and struggle for the ability to carry out its work without resorting to coercion and fear.

This seems odd from the point of view of a hierarchical organization. Theoretically, in such organizations the board acts as trustee and the director implements the board's policies. The director delegates responsibility and takes care not to scramble proper reporting relationships by becoming involved in matters that belong to subordinate supervisors. In fact, successful supportive living agencies look less neat and clear. Board members have vital roles to play, but they do not simply dictate policy because that would mean imposing unilaterally on assistive relationships and organizing the agency around power-over relationships. Team leaders have crucial roles to play, but the director will from time to time be an active participant in team work and in assistive relationships. In these instances, the director participates as a collaborator even though this may cause some confusion among workers who instinctively identify the boss only in terms of power-over. As much as any other member of the agency, the director who resorts to power-over signals a personal and organizational problem. This apparent messiness may not seem like the way it ought to be in a successful supported living agency, but it is the way it is in at least a few of them.

# III. Realizing the promise of supported living calls for new ideas about organization and management

Supported living arises from a reversal of socially devaluing assumptions. Increasing numbers of people believe that congregating and segregating people for care and treatment is unjust and unnecessary. They are convinced that it is desirable and possible for people with developmental disabilities to face the challenges and enjoy the benefits of living in a home of their own. From this point of view, the mission of publicly supported human services turns upside down from a primary concern for treatment, protection and control to a focus on assisting people to establish and live successfully in homes of their choice.

Realizing the mission of supported living calls for new ways to organize and manage work. The images of organization that emerge from innovators' experiences call for big changes in common assumptions about how to design and manage agencies. Supported living challenges both common ideas about people with disabilities and common ideas about organizations.

Viewing organizations as machines leads to poor understanding of necessary changes

Some of the problems in doing supported living are easy to see. Much of the discussion among people considering the idea concerns important, obvious questions. Can we keep people safe? Can we pay for it? Can we find real estate? Can staff adjust to new job roles and more complicated schedules? What do we do with the money that we've sunk into our buildings? A growing number of agencies have successfully tackled these and other difficult problems and demonstrated that supported living can be done successfully and over time periods as long as 10 years.

As they have solved the apparent problems, supported living innovators have run into additional problems, which lie submerged within a common sense mental picture of how organizations function. Many people take for granted that organizations are like machines, and this limits understanding of what it takes to make and sustain important changes. Managers, workers, and outside advocates frequently picture their organization as a thing outside themselves. In this view, an organization is staff and buildings configured to produce a valuable product. Necessary work is specified, delegated, and coordinated by strategic plans, organization charts, procedure manuals, and schedules. In this apparently rational picture, change means reconfiguring

the machinery by changing schedules, job descriptions, and procedure manuals, often with the help of technical assistants. Staff training adjusts workers to new arrangements. Resistance to change results from poor communication or under-use of authority and is met by sending the message again, clearer and louder.\*

Applied to the transition from residential services to supported living, the mental picture of agencies as machines oversimplifies the change process. It suggests that if system managers want a new form of service, like supported living, they should simply change what they buy through contracts or direct expenditure. If system managers want more of some valuable quality, like choice or personal relationships, they change product specifications by changing laws and regulations. The machine picture says that advocates may prevail simply by persuading a court or in a legislative body to tell system managers to tell providers to do something different. When managers who see their agencies as machines get the signal that group homes are no longer a valued product, they try to redirect the organization to produce supported living by changing plans, job descriptions, and procedures. They look to technical assistants to provide models that answer their new questions about how to find real estate, how to design jobs, how to keep people safe, how to give people more choices and a better chance at forming relationships, etc. They rely on staff trainers to "give staff the values, motivate them, and tell them how to make it work." They speak of "marketing the concept" of supported living to funding agencies and family members.

\*For helpful contrasts between the machine image and a number of other possible images of organization, see G. Morgan (1986). Images of organization. Beverly Hills: Sage. Morgan summarizes the machine image in chapter 2 and then explores 7 other, contrasting images of organization. For a useful discussion of the negative consequences of having only a machine image of organization to manage corporate life, see I. Mitroff and R. Kilmann (1984). Corporate tragedies. New York: Praeger.

This oversimplification accumulates negative effects because it leaves out much of what has to change if people with developmental disabilities are to get good support. Organizations aren't just things out there to rearrange; people belong to organizations and feel the effects of organizational life and change emotionally. Supported living challenges more than schedules, procedures, and job descriptions. It challenges people's basic understanding of their work and themselves.

Supported living advocates testify to the depth of necessary change when they describe the change from residential service to supported living as a "paradigm shift." This means, a fundamental discontinuity in the way people understand and respond to situations. This could be a helpful image to guide complex change, but the machine picture of organization abets a misconception that paradigms can be shifted as easily as one changes hairstyle. Everything from the intro-

duction of New Coke and the buttons on the fly of 501 Jeans to the General Theory of Relativity has been enthusiastically publicized as a paradigm shift. This overworks the term well beyond the point where its meaning is exhausted. Overuse misdirects people to underestimate the difficulty of such basic change. Dana Meadows\* reminds us,

A paradigm is not only an assumption about how things are; it is also a commitment to their being that way. There is an emotional investment in a paradigm because it defines one's world and oneself. A paradigm shapes language, thought, and perceptions -and systems. In social interactions, slogans, common sayings, the reigning paradigm ... is repeated and reinforced over and over, many times a day....(p. 3)

This suggests that changing a paradigm involves more than an individual conceptual makeover. It means social activity: building a community of meaning around different emotional commitments, different ways of seeing, and different ways of acting. When the machine image of organization dominates thinking, people simply try to reprogram the old organization with a new concept. The result: more of the same, but with new labels.

New images of organization fit with the reality of doing supported living better than machine images do

The machine picture of organization is popular because it has worked as a way to efficiently program many human tasks. When tasks can be analyzed and sequenced in a routine that permits easy external measurement, an organization can be set up as a simple machine. When the repertoire of standard solutions is extensive and when deciding which solution matches what problem requires expert judgement, an organization has to set up as a professional machine.

Most existing residential services operate with a mix of simple ma chine and professional machine structures. Direct service work is organized as simple machine work: jobs are specified by procedures and individual program plans. Individualization supposedly results from the activities of professionally organized teams, established by policy to decide which procedures staff should carry out to yield progress toward objectives that the team selects as meaningful. Team

judgments and management's effectiveness in insuring compliance with planned schedules are regularly monitored by outside inspectors who decide whether or not agency performance equals appropriate care and treatment.

D. Meadows (1991) The global citizen. Washington, DC: Island Press. Workers who carry out small steps at another's direction experience different status, pay, and working conditions than do professionals who exercise the discretion in the solutions they choose to apply. But both the counterperson at the fast food restaurant and the physician member of an interdisciplinary team work in organizations structured to develop and consistently deliver standardized solutions to a predefined set of problems. Whether the product is tacos or modern health care, the machine organization invests in and rewards convergent thinking toward routine solutions. Proper diagnosis and prescription means correctly identifying a defect and matching it with an approved remedy.\*

The machine picture of organization fits poorly when an agency has to solve diverse and novel problems in a rapidly changing environment. One big, non-obvious challenge facing managers who implement supported living is creating and sustaining a problem seeking organization in a system that expects and monitors and values standard performance. This challenge does not arise from reading management books; it arises from the nature of the work that must be done to support people with severe disabilities.

If supported living is going to work for people with developmental disabilities, workers in supported living agencies have to create good and lasting relationships with a variety of different individuals. Through their relationships, staff collaborate with the people they support to identify new problems and opportunities as they come up and to create new solutions as people need them. The fact that the person with a developmental disability usually depends on the supported living worker for essential assistance complicates the relationship. So does the fact that important people outside the relationship legitimately hold the supported living worker accountable for what happens to the person with a developmental disability.

The stakes in discovering new images of organization are high. When a person meets a professional worker or a direct service worker who represents an agency organized around matching people to existing solutions, only the part of that person that fits the menu of available solutions will make sense to the worker. The parts that don't fit within the agency's repertoire will be ignored. A person whose desires can't be made to fit will be sent elsewhere. But most services for people with developmental disabilities are already the elsewhere to which other systems send those whose needs and desires don't fit their preferred set of solutions. So a growing number of people end up

\* For a helpful discussion of important similarities between professional human service work and assembly line work and a discussion of the ironic effects of trying to redefine the outcomes of the special education system while still under the spell of the machine picture of organization see T. Skrtik (1991). Behind special education: A critical analysis of professional culture and school organization. Denver: Love Publishing. L. Thomas (1983). *The* youngest science: Notes of a medicine watcher, NY: Viking Press, describes the changes as technological advances have organized the practice of medicine as a professional machine. H. Mintzberg (1989). On management: Inside our strange world of organizations. New York: Free Press, discusses the benefits, limitations and costs of managing as if our organizations were machines and describes several other organizational configurations that make a better fit with different technical and environmental conditions.

with no alternative. Those who cannot leave and persist in resisting the organization's preferred solutions risk being rejected by those they must continue to rely on for the most basic daily assistance. The mutual frustration produced by this interpersonal bind pushes people to withdrawal, burnout, and violence.

Working in a residential facility, even a very small one, can be like working on an assembly line. Working effectively in supported living has to be more like inventing and negotiating solutions to political problems. When an ongoing fight between a person and her roommate leads neighbors to complain to the landlord or when a person decides to stop taking his medication, procedures and past experience may provide a guide for negotiating a balance among competing interests in a way that preserves important values, but there are no self-administering prescriptions.

E.F. Schumacher contrasts convergent problems, which have one best answer with divergent problems which call for a widening variety of responses and usually involve dealing creatively with conflicts of value. Doing supported living means organizing to support people in dealing with divergent problems. Schumacher\* describes the everyday art of dealing with divergent problems:

...through all our lives we are faced with the task of reconciling opposites which, in logical thought cannot be reconciled.... How can one reconcile the demand for freedom and discipline in education? Countless mothers and teachers, in fact do it everyday, but no one can write down a solution. They do it by bringing into the situation a force that belongs to a higher level where opposites are transcended the power of love. Divergent problems force people to strain themselves to a level above themselves; divergent problems demand, and thus provide the supply of, forces from a higher level, thus bringing love, beauty, goodness, and truth into our lives. It is only with the help of these higher forces that opposites can be reconciled in the living situation, (p. 76)\*

The work of supporting people with developmental disabilities doesn't demand extraordinary creativity; it calls for the sort of ordinary creativity that machine imaged organizations program out. The important abilities have to do with forming and sustaining relationships, listening and looking and thinking carefully, and inventing solutions to everyday problems.

\* E. Schumacher. (1973) Small is beauti ful: Economics as if people mattered. London: Blond & Briggs. Experience shows that many ordinary people have the skills and talent to master the art of assisting disabled people to make and keep their place in community. All that is necessary for ordinary creativity to flower is that organizations develop ways to enlist and expand their worker's commitment to better lives for the people they serve and their discipline in learning to become better collaborators with the people they assist.